

Project: ICICE
Document: Child Patient Survey – Version 4 (*child under age 12*)
Revised: 1/29/01
Revised by: SRG and Rita Mangione-Smith, MD

ICICE Patient Interview

Parent of Child with Asthma (age 2-11)



INTRODUCTION OF STUDY TO RESPONDENT

Hello, my name is [FIRST AND LAST NAME]. May I speak with [R's NAME]?

I'm calling to follow up on a letter we sent you about research [FILL SITE NAME] and RAND are conducting on children with asthma. The letter was mailed on [DATE] and mentioned that an interviewer from RAND would be calling to request a telephone interview and to answer any questions you have about this study.

Do you remember getting the letter?

If Yes, go to >study<

If No, go to >nolet<

For respondents who don't remember getting letter:

>nolet<

The letter was from [fill SITE CO-SIGNER] of [fill SITE NAME] and Dr. Emmett Keeler, a researcher at RAND. The letter invited you to take part in research to improve the care of children who receive care for asthma from [fill SITE NAME]. The letter mentioned two telephone interviews and your child's health care records.

We are calling now to ask you to take part in the first telephone interview.

Of course participation in the study is voluntary. You can stop the interview or refuse to answer a question at any time. Your decision to take part will not affect the care your family gets from [[fill SITE NAME] in any way. RAND will not give your child's doctors a copy of the answers you give in the interview. Any and all study results will be reported only at the group level. No individual person's information will be published separately in any report of results. The information we give to [fill SITE NAME], to help them improve the care they give to children with asthma will be limited to group summaries and statistics.

As a token of our thanks we will send you \$10 for taking part in this interview. With your permission, your answers to the interview will be combined with information from your child's health care records from [fill SITE NAME]. We have found that the additional information we can collect from your child's health care records is very valuable as it helps us to complete the picture of your child's health and the care (he/she) gets.

This screen is used to confirm the listed adult is the person who knows most about the child's asthma.

>proxy<

Before we begin, I just want to make sure the information we got from [fill SITE NAME] is correct. Their records list you as the person in your family who knows the most about [fill CHILD NAME] and (his/her) asthma. Is this right?

- 1 Yes, [fill R's NAME] is the right person to interview.
- 2 No, someone else in family knows most about child's asthma. (Go to respondent identification screens)
- 3 R requests remail of letter before deciding to take part. (Set Call Back and complete remail request slip)
4. R says child doesn't have asthma.
5. R says child no longer lives at this address. (Go to tracking screens)
- x Schedule a Call Back

Race, Ethnicity

AA3. How would you describe your child's race or ethnicity? Is your child:

- | | |
|-----------------------------|-------------------------------|
| 1 Latino or Hispanic | 4 Asian or Pacific Islander |
| 2 White | 5 Another race or multiracial |
| 3 Black or African-American | |

A. Type and Duration of Asthma

REF: A1-A2: Adapted from RAND's ICICE Baseline Interview for Diabetes Patients®

I have some general questions about your child's asthma.

A1. Has a doctor ever told you that your child has asthma?

PROBE: Your child's doctor may have called this reactive airway disease, or wheezy bronchitis.

- | | |
|-------------------|------|
| 1 Yes →Skip to A2 | 2 No |
| 3 Don't Know | |

A1a. We'll check our records again. Another interviewer may call you back in the next week or so to follow-up. INTERVIEWER CODE CASE AS "PROBLEM".

A2. How long has (he/she) had asthma?

Enter Number of Years: _____ →Skip to B1

OR, If Don't Know/Don't Remember, →Ask A2a

A2a. Has (he/she) had asthma for

- 1 Less than a year
- 2 1 to 5 years
- 3 More than 5 years

B. Adherence

B1. Do you check your child's peak flows at home?

DEFINITION: This is where your child blows air as hard as (he/she) can into a tube that measures how bad (his/her) asthma is by giving you a number, for example 150 or 200.

- | | |
|-------|-------------------|
| 1 Yes | 5 No → Skip to B3 |
|-------|-------------------|

B2. During the last 4 weeks, how often did you check (his/her) peak flows at home? Was it:

- | | |
|-------------------------|-----------------------|
| 1 Never | 4 Once a day |
| 2 Less than once a week | 5 Twice a day or more |
| 3 A few times per week | |

B3. Some children with asthma take daily inhaled medications to help keep their asthma under control. For example, they use a steroid inhaler like Vanceril or Beclovent. Is this something your child's doctor has prescribed?

DEFINITION: A daily inhaler contains longer-lasting asthma medicine that your child "puffs" or inhales. It helps prevent asthma symptoms and attacks from happening.

INTERVIEWER: If R mentions cortisone inhaler, code "yes" and say: "Think of your child's inhaler as you answer these next few questions."

- | | |
|-------------------------|-------------------|
| 1 Yes | 5 No → Skip to B6 |
| d Not Sure → Skip to B6 | |

B4. I need to know which kind of daily inhaler your child's doctor prescribed. Can you tell me what color it is, or the name of the medication? (I can wait while you go get it.)

- 1 Name or Colors match daily inhalers listed on sheet.
- 2 Name or Colors match fast-acting inhalers listed on sheet.
- 3 Name or Colors do not match any inhaler listed on sheet.

(Enter Name/Colors: _____)

STEROID INHALERS TO BE COUNTED IN B4:

COLOR	MEDICATION NAME
GRAY WITH A PURPLE CAP	AEROBID (ARROW-BID)
LIGHT GREEN WITH A DARK GREEN CAP	AEROBID (ARROW-BID)
WHITE WITH WHITE CAP	AZMACORT (ASTHMA-COURT)
TAN WITH A BROWN CAP	BECLOVENT (BECK-LOW-VENT)
DARK ORANGE WITH A LIGHT ORANGE CAP.	FLOVENT (FLOW-VENT)
WHITE AND BROWN TUBE	PULMICORT (PUHL-MIH-COURT)
PINK WITH A PURPLE CAP	VANCERILL (VAN-SIR-ILL)

FAST ACTING INHALERS SHOULD NOT BE COUNTED IN B4:

COLOR	MEDICATION NAME
WHITE WITH WHITE CAP	ALBUTEROL (AL-BEW-TER-ALL)
LIGHT BLUE WITH DARK BLUE CAP	ALBUTEROL (AL-BEW-TER-ALL) OR VENTOLIN (VEN-TOE-LIN)
CLEAR WITH BLUE CAP	ALUPENT (AL-YOU-PENT)
WHITE WITH BLUE CAP	ALUPENT (AL-YOU-PENT) OR INTAL (IN-TALL)
CLEAR WITH GREEN CAP	ATROVENT (AT-ROW-VENT)
WHITE WITH GREEN CAP	ATROVENT (AT-ROW-VENT)
YELLOW WITH AN ORANGE CAP	PROVENTILL (PRO-VENT-ILL)
WHITE WITH GREEN LETTERS ON TUBE AND CAP	TILADE (TIE-LADE)

QXQ ISSUE: CAN'T DISTINGUISH FROM AZMACORT, SO GIVE CREDIT IN B4

- B5. During the last 4 weeks, how often was your child able to use (his/her) inhalers as directed by (his/her) doctor? Was it:
- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |
- B6. Some parents whose children have asthma do special things at home to help keep their child's asthma under control. For example, they put plastic covers over their child's mattress and pillow or they vacuum carpets more often. Has your child's doctor suggested you to do things like this to help control (his/her) asthma?
- | | |
|----------------------------------|--------------------------|
| 1 Yes | 5 No → Skip to C1 |
| d Don't Know → Skip to C1 | |
- B7. How many of the doctors' suggestions have you been able to do? Would you say:
- | | |
|--------|--------|
| 1 All | 3 Some |
| 2 Most | 4 None |

C. Self-Efficacy and Perceived Control

I'm going to read you some statements about your child's asthma. For each one, I'll ask you how much you disagree or agree with the statement.

REF: C1 Adapted from: Katz PP, Yelin EH, Smith S, and Blanc PD. "Perceived Control of Asthma: Development and Validation of a Questionnaire," *American Journal of Respiratory Critical Care Medicine*, 155(2):577-82, Feb 1997.

C1. If I do all the right things, I can successfully manage my child's asthma. Do you:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

REF: C2 through C9 Adapted from: Bursch, B., Schwankovsky, L., Gilbert, J., Zeiger, R. "Construction and Validation of Four Childhood Asthma Self-Management Scales: Parent Barriers, Child and Parent Self-Efficacy, and Parent Belief in Treatment Efficacy," *Journal of Asthma*, 36(1):115-128, 1999.

C2. I know the correct way for my child to take (his/her) asthma medications. Do you:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

C3. It's difficult to get my child to take (his/her) asthma medications. Do you:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

C4. Once my child starts wheezing and coughing it is hard for me to keep (his/her) symptoms from getting worse. Do you:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

- C5. I know how to help my child stay calm when (he/she) is having a serious breathing problem. Do you:
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |
- C6. I know which medications to give my child when (he/she) is having a serious breathing problem. Do you:
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |
- C7. It is hard for my child to avoid allergens (like dust, mold, cat or dog hair) and other things (like tobacco smoke, perfume) that cause (him/her) to have asthma symptoms. Do you:
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |
- C8. I know when my child's breathing problems are serious enough to go to the emergency room. Do you:
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |
- C9. I know how to use a peak flow meter to measure how my child's asthma is doing. Do you:
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D. Knowledge

REF: All items adapted or taken directly from: National Asthma Education Program, Office of Prevention, Education, and Control, National Heart, Lung, and Blood Institute. Bethesda, MD: National Institutes of Health, Publication No. 91-3042, August 1991.

- D1. Daily inhalers (like Vanceril or Flow vent) are for quick relief of coughing or problems breathing.
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |
- D2. Asthma attacks are not really harmful or dangerous.
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |
- D3. Asthma attacks usually occur suddenly without warning.
- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D4. Many different things can bring on an asthma attack.

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D5. Asthma cannot be cured, but it can be controlled.

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D6. People with asthma can't to monitor how well their lungs are working.

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D7. Being around tobacco smoke can make a child's asthma worse.

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D8. Children with asthma should not exercise.

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D9. Avoiding things that cause allergic reactions (like pet cats or dust) is helpful in preventing asthma attacks.

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

D10. Keeping a child calm will help keep a serious breathing problem from getting worse.

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
| 3 Neither disagree nor agree | |

E. Health Related Quality of Life

REF: E1-E16: PedsQL (Pediatric Quality of Life Inventory), Parent Report for Children (ages 2-4), Version 4 Short Form (SF15); Copyright © 1998, JW Varni, PhD. Address correspondence to: James W. Varni, PhD, Professor and Senior Scientist, Center for Child Health Outcomes, Children's Hospital and Health Center, 3020 Children's Way, San Diego, CA 92123

PROGRAMMING NOTE: If child is age 2-4, ask E1. ALL OTHERS SKIP TO E17.

The next questions are about things that might be a problem for your child. For each kind of activity I read, please tell me how much of a problem it was for your child during the past month. Keep in mind there are no right or wrong answers.

- E1. During the past month, has walking been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E2. During the past month, has running been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E3. During the past month, has taking part in active play or exercise been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E4. During the past month, has lifting something heavy been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E5. During the past month, has helping to pick up his or her toys been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E6. During the past month, has feeling afraid or scared been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E7. During the past month, has feeling sad or blue been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E8. During the past month, has feeling angry been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E9. During the past month, has worrying been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E10. During the past month, has playing with other children been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E11. During the past month, has other kids not wanting to play with (him/her) been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E12. During the past month, has getting teased by other children been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E13. In the past month, did your child attend school or daycare?

- | | |
|-------|---------------------------|
| 1 Yes | 5 No → Skip to E49 |
|-------|---------------------------|

E14. During the past month, has doing the same school or daycare activities as peers been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E15. During the past month, has missing school or daycare because of not feeling well been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E16. During the past month, has missing school or daycare to go to the doctor or hospital been a problem for your child:

- | | |
|-----------------|----------------------|
| 1 Never | → Skip to E49 |
| 2 Almost never | → Skip to E49 |
| 3 Sometimes | → Skip to E49 |
| 4 Often | → Skip to E49 |
| 5 Almost always | → Skip to E49 |

E17. PROGRAMMING NOTE: If child is age 5-7, ask E18. All others Skip to E33.

The next questions are about things that might be a problem for your child. For each kind of activity I read, please tell me how much of a problem it was for your child during the past month. Keep in mind there are no right or wrong answers.

REF: E18-E32: PedsQL (Pediatric Quality of Life Inventory), Parent Report for Children (ages 5-7), Version 4 Short Form (SF15) ; Copyright © 1998 JW Varni, PhD. Address correspondence to: James W. Varni, PhD, Professor and Senior Scientist, Center for Child Health Outcomes, Children's Hospital and Health Center, 3020 Children's Way, San Diego, CA 92123

E18. During the past month, has walking more than one block been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

- E19. During the past month, has running been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E20. During the past month, has taking part in sports activity or exercise been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E21. During the past month, has lifting something heavy been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E22. During the past month, has doing chores, like picking up his or her toys been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E23. During the past month, has feeling afraid or scared been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E24. During the past month, has feeling sad or blue been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E25. During the past month, has feeling angry been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E26. During the past month, has worrying about what will happen to him or her been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E27. During the past month, has getting along with other children been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E28. During the past month, has other kids not wanting to be (his/her) friend been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E29. During the past month, has getting teased by other children been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E30. During the past month, has paying attention in class been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E31. During the past month, has forgetting things been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E32. During the past month, has keeping up with school activities been a problem for your child:

- | | |
|-----------------|---------------|
| 1 Never | → Skip to E49 |
| 2 Almost never | → Skip to E49 |
| 3 Sometimes | → Skip to E49 |
| 4 Often | → Skip to E49 |
| 5 Almost always | → Skip to E49 |

E33. PROGRAMMING NOTE: If child is age 8-11, ask E34. All others skip to E49.

The next questions are about things that might be a problem for your child. For each kind of activity I read, please tell me how much of a problem it was for your child during the past month. Keep in mind there are no right or wrong answers.

REF: E34-E48: PedsQL (Pediatric Quality of Life Inventory), Parent Report for Children (ages 8-12), Version 4 Short Form (SF15); Copyright © 1998 JW Varni, PhD. Address correspondence to: James W. Varni, PhD, Professor and Senior Scientist, Center for Child Health Outcomes, Children's Hospital and Health Center, 3020 Children's Way, San Diego, CA 92123

E34. During the past month, has walking more than one block been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E35. During the past month, has running been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

- E36. During the past month, has taking part in sports activity or exercise been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E37. During the past month, has lifting something heavy been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E38. During the past month, has doing chores around the house been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E39. During the past month, has feeling afraid or scared been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E40. During the past month, has feeling sad or blue been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E41. During the past month, has feeling angry been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E42. During the past month, has worrying about what will happen to him or her been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E43. During the past month, has getting along with other children been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E44. During the past month, has other kids not wanting to be (his/her) friend been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E45. During the past month, has getting teased by other children been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E46. During the past month, has paying attention in class been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E47. During the past month, has forgetting things been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E48. During the past month, has keeping up with schoolwork been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E49. PROGRAMMING NOTE: If child age 2-4, ask E50. All others, Skip to E70.

REF: E50-E70 - PedsQL (Pediatric Quality of Life Inventory) Asthma Module, Parent Report for Children (ages 2-4), Version 3 Short Form (SF22); Copyright © 1998 JW Varni, PhD. Address correspondence to: James W. Varni, PhD, Professor and Senior Scientist, Center for Child Health Outcomes, Children's Hospital and Health Center, 3020 Children's Way, San Diego, CA 92123

E50. During the past month, has pain or tightness in (his/her) chest been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E51. During the past month, has feeling wheezy been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E52. During the past month, has having asthma attacks been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E53. During the past month, has getting scared while having asthma attacks been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

- E54. During the past month, has getting out of breath been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E55. During the past month, has coughing been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E56. During the past month, has taking a deep breath been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E57. During the past month, has having a stuffy or runny nose been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E58. During the past month, has waking up at night with trouble breathing or coughing been a problem for your child:
- | | |
|------------------------------|-----------------|
| 1 Never → Skip to E60 | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E59. About how many nights (in the past month) did that happen?
- Enter Number of Nights: _____ (0-31) → **Skip to E60**
- d Don't Know
- r Refuse → **Skip to E60**
- E59A. Was it:
- | |
|----------------------|
| 1 Less than 3 times |
| 2 3 to 4 times |
| 3 5 to 10 times |
| 4 More than 10 times |
- E60. During the past month, has playing with pets been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E61. During the past month, has playing outside been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E62. During the past month, has medicines making (him/her) feel sick been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

- E63. During the past month, has trouble sleeping because of medicines been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E64. During the past month, has trouble using his or her inhaler been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E65. During the past month, has not liking to carry (his/her) inhaler been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E66. During the past month, has refusing to take medicines been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E67. During the past month, has forgetting to take medicines been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E68. During the past month, has getting anxious when (he/she) has to have medical treatments been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E69. During the past month, has getting anxious about going to the doctor been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E70. During the past month, has getting anxious about going to the hospital been a problem for your child:
- | | |
|-----------------|--------------|
| 1 Never | → Skip to F1 |
| 2 Almost never | → Skip to F1 |
| 3 Sometimes | → Skip to F1 |
| 4 Often | → Skip to F1 |
| 5 Almost always | → Skip to F1 |
- E71. PROGRAMMING NOTE: If child is age 5-11, ask E72. All others, Skip to F1.

REF: E72-E94: PedsQL (Pediatric Quality of Life Inventory) Asthma Module, Parent Report for Children (ages 5-11), Version 3 Short Form (SF22); Copyright © 1998 JW Varni, PhD. Address correspondence to: James W. Varni, PhD, Professor and Senior Scientist, Center for Child Health Outcomes, Children's Hospital and Health Center, 3020 Children's Way, San Diego, CA 92123

E72. During the past month, has pain or tightness in (his/her) chest been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E73. During the past month, has feeling wheezy been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E74. During the past month, has having asthma attacks been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E75. During the past month, has getting scared while having asthma attacks been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E76. During the past month, has getting out of breath been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E77. During the past month, has coughing been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E78. During the past month, has taking a deep breath been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E79. During the past month, has having a stuffy or runny nose been a problem for your child:

- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E80. During the past month, has waking up at night with trouble breathing or coughing been a problem for your child:

- | | |
|------------------------------|-----------------|
| 1 Never → Skip to E82 | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

E81. About how many nights (in the past month) did that happen?

Enter Number of Nights: _____ (0-31) → **Skip to E82**

d Don't Know

r Refuse → **Skip to E82**

E81A. Was it:

- 1 Less than 3 times
- 2 3 to 4 times
- 3 5 to 10 times
- 4 More than 10 times

E82. During the past month, has playing with pets been a problem for your child:

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Often
- 5 Almost always

E83. During the past month, has playing outside been a problem for your child:

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Often
- 5 Almost always

E84. During the past month, has medicines making (him/her) feel sick been a problem for your child:

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Often
- 5 Almost always

E85. During the past month, has trouble sleeping because of medicines been a problem for your child:

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Often
- 5 Almost always

E86. During the past month, has trouble using his or her inhaler been a problem for your child:

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Often
- 5 Almost always

E87. During the past month, has not liking to carry (his/her) inhaler been a problem for your child:

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Often
- 5 Almost always

E88. During the past month, has being responsible for (his/her) medicines been a problem for your child:

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Often
- 5 Almost always

E89. During the past month, has controlling his or her asthma been a problem for your child:

- 1 Never
- 2 Almost never
- 3 Sometimes
- 4 Often
- 5 Almost always

- E90. During the past month, has refusing to take medicines been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E91. During the past month, has forgetting to take medicines been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E92. During the past month, has getting anxious when (he/she) has to have medical treatments been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E93. During the past month, has getting anxious about going to the doctor been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |
- E94. During the past month, has getting anxious about going to the hospital been a problem for your child:
- | | |
|----------------|-----------------|
| 1 Never | 4 Often |
| 2 Almost never | 5 Almost always |
| 3 Sometimes | |

F. Impact on Family Functioning

REF: All items in this section are adapted from: Stein, R.E.K., Riessman, C.K. "The Development of an Impact-on-Family Scale: Preliminary Findings," *Medical Care* 18(4): 465-472, 1980.

I am going to read some statements that people have made about living with child who has asthma. For each statement, please tell me whether you disagree or agree.

Familial Social Impact Subscale:

- F1. People in the neighborhood treat us special because of my child's illness. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
- F2. We have little desire to go out because of my child's illness. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
- F3. Our family gives up things because of my child's illness. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
- F4. I don't have much time left for other family members after caring for my child with asthma. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |

Personal Strain Subscale:

- F5. Nobody understands the burden I carry. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
- F6. Traveling to see the doctor is a strain on me. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
- F7. Sometimes I feel like we live on a roller coaster: in crisis when my child is acutely ill, OK when things are stable. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |

Mastery Subscale:

- F8 Learning to manage my child's illness has made me feel better about myself. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |
- F9. Because of what we have shared we are a closer family. Do you:
- | | |
|---------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly Agree |

G. Asthma-Related Symptoms, Disease Control, and Severity

Ref: Practical Guide for the Diagnosis and Management of Asthma; Based on the Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma. U.S. Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute. NIH Publication No. 97-4053; pg. 10, Figure 3 and pg. 13, Figure 6, October 1997

These next questions are about your child's asthma symptoms.

- G1. During the past week, on how many days did your child have asthma symptoms during the daytime? Was it:
- | | |
|--------------------|-------------|
| 0 No days | 3 Every day |
| 1 Less than 3 days | 4 Not Sure |
| 2 3 to 6 days | |
- G2. During the past week, did your child use a fast acting or quick relief medication (e.g. Albuterol, Ventolin, Proventil) from an inhaler?
- DEFINITION: Fast acting inhalers contain medication that your child "puffs" or inhales to get quick relief from coughing or breathing problems.
- | | |
|--------------------------|--------------------------------|
| 1 Yes | 3 Not Sure → Skip to G5 |
| 5 No → Skip to G5 | |
- G3. In the past week, about how many times each day did your child use fast acting or quick relief medication?
- | | |
|--------------------|---------------------|
| 0 Not at all | 3 More than 6 times |
| 1 1 to 3 times | 4 Not Sure |
| 2 4 to 6 times, or | |

G4. I need to know which kind of fast acting or quick relief inhaler your child used. Can you tell me what color it is? (I can wait while you go get it.)

- 1 Name or Colors match fast-acting inhalers on sheet.
- 2 Name or Colors match steroid inhalers on sheet.
- 3 Name or Colors do not match any inhaler on sheet.

(Enter NAME/COLORS: _____)

FAST ACTING/QUICK RELIEF INHALERS TO BE COUNTED IN G4

COLOR	MEDICATION NAME
WHITE WITH WHITE CAP	ALBUTEROL (AL-BEW-TER-ALL)
LIGHT BLUE WITH DARK BLUE CAP	ALBUTEROL (AL-BEW-TER-ALL) OR VENTOLIN (VEN-TOE-LIN)
CLEAR WITH BLUE CAP	ALUPENT (AL-YOU-PENT)
WHITE WITH BLUE CAP	ALUPENT (AL-YOU-PENT) OR INTAL (IN-TALL)
CLEAR WITH GREEN CAP	ATROVENT (AT-ROW-VENT)
WHITE WITH GREEN CAP	ATROVENT (AT-ROW-VENT)
YELLOW WITH AN ORANGE CAP	PROVENTILL (PRO-VENT-ILL)
WHITE WITH GREEN LETTERS ON TUBE AND CAP	TILADE (TIE-LADE)

QXQ ISSUE: CAN'T DISTINGUISH FROM AZMACORT, SO GIVE CREDIT IN G5

STERIOD INHALERS SHOULD NOT BE COUNTED IN G4:

COLOR	MEDICATION NAME
GRAY WITH A PURPLE CAP	AEROBID (ARROW-BID)
LIGHT GREEN WITH A DARK GREEN CAP	AEROBID (ARROW-BID)
WHITE WITH WHITE CAP	AZMACORT (ASTHMA-COURT)
TAN WITH A BROWN CAP	BECLOVENT (BECK-LOW-VENT)
DARK ORANGE WITH A LIGHT ORANGE CAP.	FLOVENT (FLOW-VENT)
WHITE AND BROWN TUBE	PULMICORT (PUHL-MIH-COURT)
PINK WITH A PURPLE CAP	VANCERILL (VAN-SIR-ILL)

- G5. During the past 4 weeks, has your child had more asthma symptoms at home or at school?
- 1 Home 2 School 3 Not Sure
- G6. During the past 6 months, did your child miss any overnight camping trips or sleepovers at a friend's house because (he/she) had breathing problems at night?
- 1 Yes 5 No
- G7. In the past 6 months, did your child have an asthma attack that was so bad (he/she) had to see a see a doctor right away that same day?
- 1 Yes 5 No

Now I'm going to ask some questions about health care (CHILD NAME) may have had.

- G8. Has your child ever had to stay overnight in the hospital because of asthma?
- 1 Yes 5 No → **Skip to H1**
- G9. Has your child ever been put on a ventilator where the doctors had to put a tube down your child's throat and a machine had to breathe for (him/her)?
- 1 Yes 5 No

H. Patient Satisfaction

REF: H1-H2: Adapted from "CAHPS™ 2.0 Survey and Reporting Kit," U.S. Department of Health and Human Services, Public Health Services. Agency for Healthcare Research and Quality. AHRQ Publication Number 99-0039, October 1999.

- H1. These next questions are about your child's asthma care provider. This is the doctor or other health provider your child sees most often for care related to (his/her) asthma.
- Does your child have one doctor or other health provider (he/she) goes to for care related to asthma?

1 Yes 5 No → **Skip to H6**

- H2. Is (his/her) asthma care provider:

INTERVIEWER INSTRUCTION: Nurses and physician assistants should always be coded 3 even if R reports they have a specialty.

- 1 A general pediatrician or a family medicine doctor
 2 An asthma specialist (like a pulmonologist, or an allergy specialist)
 3 A nurse or physician assistant
 4 Or someone else (SPECIFY)_____

- H3. How long has your child been seeing (his/her) asthma care provider? Is it:

DEFINITION: An asthma care provider is the person your child sees most often for care related to (his/her) asthma.

- 1 Less than 6 months 4 2 to 5 years
 2 6 to 12 months 5 5 years or more
 3 12 to 24 months,

- H4. In the past 6 months, did your child see (his/her) asthma care provider?

1 Yes 5 No → **Skip to H6**

H5. We want to know your overall rating of the health provider your child sees most often for asthma care.

Use any number from 0 to 10 where 0 is the worst asthma care provider possible and 10 is the best asthma care provider possible. How would you rate your child's asthma care provider in the past 6 months? (If (he/she) saw more than one provider for asthma please rate the provider (he/she) saw most often)

ENTER NUMBER: _____

PROGRAMMING NOTE: H7 is skipped if H4 is coded 1 (Yes). (Respondent visited asthma care provider in past 6 months.)

H6. In the past 6 months, did your child see a doctor or other health provider for care related to (his/her) asthma?

1 Yes

5 No →**Skip to H13**

H7. These next questions are about all health care providers who treated your child's asthma in the past 6 months, not just the person he/she saw most often. Include all of the doctors, nurses, educators and any other health provider who helped you and your child take care of his/her asthma in your answers to these questions.

In the past 6 months, how often did the health care providers who treated your child's asthma listen carefully to you? Was it:

1 Never

3 Usually

2 Sometimes

4 Always

H8. In the past 6 months, how much of a problem, if any, was getting the care you or your child's health care provider believed necessary for your child's asthma? Was it:

1 A big problem

2 A small problem

3 Not a problem

H9. In the past 6 months, how often did the health providers who treated your child's asthma explain things in a way you could understand? Was it:

1 Never

3 Usually

2 Sometimes

4 Always

H10. In the past 6 months, how often did the health providers who treated your child's asthma show respect for what you had to say? Was it:

1 Never

3 Usually

2 Sometimes

4 Always

H11. In the past 6 months, how often did the health providers who treated your child's asthma spend enough time with you? Was it:

1 Never

3 Usually

2 Sometimes

4 Always

H12. We want to know your overall rating of all your child's asthma care in the past 6 months from all doctors, nurses, educators and any other health providers who helped you and your child take care of (his/her) asthma.

Use any number from 0 to 10 where 0 is the worst asthma care possible and 10 is the best asthma care possible. How would you rate all your child's asthma care in the past 6 months?

Enter NUMBER: _____

REF: H13-H18: Adapted from set from the Sandi MacColl Institute for Healthcare Innovation, Group Health Coop., Puget Sound, Seattle, WA.

H13. Please tell me how much you disagree nor agree in general with the following statements about the health providers who treated your child's asthma.

My child's asthma care providers have given me choices and options about my child's asthma treatment. Do you:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree nor agree | |

H14. My child's health providers have given me confidence that I can make changes in my child's life to control (his/her) asthma:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree nor agree | |

H15. My child's asthma care providers are interested in my questions . Do you:

IF NEEDED: Give me the answer that comes closest to your experience most of the time.

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree nor agree | |

H16. At least one of my child's health providers regularly reviews with me how our family is doing in managing all aspects of my child's asthma. Do you:

- | | |
|------------------------------|------------------|
| 1 Strongly disagree | 4 Agree |
| 2 Disagree | 5 Strongly agree |
| 3 Neither disagree nor agree | |

H17. Have your child's asthma care providers worked with you to develop a plan so that you know how to take care of your child's asthma?

- | | |
|-------|---------------------------|
| 1 Yes | 5 No → Skip to H20 |
|-------|---------------------------|

H18. Do you have a copy of this plan in writing?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

H19. Is there a written action plan for your child's asthma on file at (his/her) school?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

REF: H20: Adapted from set from the Sandi MacColl Institute for Healthcare Innovation, Group Health Coop., Puget Sound, Seattle, WA.

H20. Did your child's asthma care providers work with you to set personal goals for your child's asthma treatment?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

REF: H21-H22: Adapted from RAND's ICICE Baseline Interview for Diabetes Patients®

H21. In the past 6 months, did you get a letter, a postcard, or a call to remind you about appointments for asthma care?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

H22. In the last 6 months did any of the health providers who treat your child's asthma call you to check and see how your child was doing without you calling them first?

1 Yes 5 No

H23. Certain things like tobacco smoke, dust, pets or animal hair, cockroaches, and mold can make asthma worse. In the last 6 months have any of your child's asthma care providers talked with you about ways to avoid these kinds of things?

1 Yes 5 No

I. Patterns of Service Use

REF: I1-I3: Adapted from RAND's ICICE Baseline Interview for Diabetes Patients®

I'm going to read you a list of health providers your child might have seen.

I1. Has your child ever seen an asthma specialist like a pulmonologist, or an allergy specialist?

1 Yes
5 No **Skip to I3**
d Don't Know **Skip to I3**

I2. Was that visit in the last six months?

1 Yes 5 No

I3. In the past 6 months, did your child see an asthma educator?

DEFINITION: An asthma educator is a health provider who teaches you and your child how to take medications, avoid asthma triggers, and tells you what to do to keep your child's asthma under control. An asthma educator often follows up with you to make sure you remember how to do these things after being taught.

1 Yes 5 No d Don't Know

I4. Has your child's doctor ever explained the possible side effects of your child's asthma medications?

1 Yes 5 No → **Skip to J1** d Don't Know → **Skip to J1**

I5. Did your child's doctor answer none, some most or all of your questions about side effects from your child's asthma medications?

1 None 3 Most
2 Some 4 All

I6. How worried are you about the side effects of your child's asthma medications?

1 A lot 2 A little 3 Not at all

J. Education

REF: Adapted from RAND's ICICE Baseline Interview for Diabetes Patients®. Content based on information obtained from: Practical Guide for the Diagnosis and Management of Asthma; Based on the Expert Panel Report 2: Guidelines for the Diagnosis and Management of Asthma. U.S. Department of Health and Human Services, National Institutes of Health, National Heart, Lung, and Blood Institute. NIH Publication No. 97-4053; October 1997

[Estimated length: 1.4 minutes]

These next questions are about materials or programs you may have received or taken part in during the past 6 months.

- J1. (In the past 6 months) did you get any materials, like a newsletter, magazine, pamphlet, or videotape on your child's asthma?
1 Yes 5 No
- J2. In the past 6 months did you get any one-on-one educational or counseling sessions on caring for your child's asthma?
1 Yes 5 No
- J3. In the past 6 months did you or your child attend any group classes to learn more about asthma?
1 Yes 5 No
- J4. In the past 6 months did any of your child's asthma care providers go over with you and your child how to use a peak flow meter?
1 Yes 5 No
- J5. In the past 6 months did your child's asthma care providers go over with you how to help your child properly use (his/her) asthma medications?
1 Yes 5 No
- J6.. (In the past 6 months) did you get any information about asthma from the internet or visit a web site about asthma?
1 Yes 5 No

K. Chronic Conditions

REF: Adapted from RAND's ICICE Baseline Interview for Diabetes Patients[®]

Now I would like to ask you about other health conditions your child may have.

- K1. Does your child have diabetes?
PROBE: Has a doctor ever told you that your child has diabetes?
1 Yes 5 No → **Skip to K2**
- K1a. Does your child receive treatment for it?
1 Yes 5 No
- K1b. Does it limit your child's activities?
1 Yes 5 No
- K2. Does your child have chronic lung disease other than asthma?
DEFINITION: Chronic lung diseases include lung disease your child has because he or she was born early, cystic fibrosis or any other lung disease a doctor has told you that your child has.
1 Yes 5 No → **Skip to K3**
- K2a. Does your child receive treatment for it?
1 Yes 5 No
- K2b. Does it limit your child's activities?
1 Yes 5 No
- K3. Does your child have a frequent runny nose and congestion? Doctors sometimes call this chronic sinusitis, hay fever or allergies.
1 Yes 5 No → **Skip to K4**

K3a. Does your child receive treatment for it?

1 Yes 5 No

K3b. Does it limit your child's activities?

1 Yes 5 No

K4. Does your child have any other serious health problems?

1 Yes (SPECIFY): _____

5 No → **Skip to L1**

K4a. Does your child receive treatment for [fill K4]?

1 Yes 5 No

K4b. Does it limit your child's activities?

1 Yes 5 No

K5. Does your child have any other serious health problems?

1 Yes (SPECIFY): _____

5 No → **Skip to L1**

K5a. Does your child receive treatment for [fill K5]?

1 Yes 5 No

K5b. Does it limit your child's activities?

1 Yes 5 No

L. Demographics

These next questions are about you and will help us to describe all the parents and caregivers who take part in this study.

L1. How are you related to [CHILD'S NAME]?

- 1 Mother/Father (including Step-Parent)
- 2 Grandparent
- 3 Brother/Sister
- 4 Aunt/Uncle
- 5 Foster Parent
- 6 Legal Guardian
- 7 Other (SPECIFY: _____)

Smoking

L2. Do you currently smoke or use tobacco?

1 Yes → **Go to L3** 2 No → **Skip to L4**

L3. In the last 6 months, were you advised to quit smoking by your child's doctor?

- 1 Yes
- 5 No
- n I did not see my child's doctor in past 6 months.

L4. Does anyone else who lives with (CHILD NAME) smoke or use tobacco?

1 Yes 5 No d Don't Know

L18. In the past 6 months, how many times did (CHILD NAME) go to the emergency room? (Your best estimate is fine.)

PROBE: Include all of your child's health care in your answer, not just care related to asthma.

Enter Number: _____ (acceptable range is 0-15 times)

L19. In the past 6 months, how many times did your child spend one night or more in the hospital? (Your best estimate is fine).

PROBE: Include all of your child's health care in your answer, not just care related to asthma.

Enter Number: _____ (acceptable range is 0-15 times) If ZERO nights, **Skip to L24**

If L19 = 1

L20. How many nights did your child spend in the hospital?

Enter Number: _____ (acceptable range is 0-50 nights) **Skip to L24**

If L19 ≥ 2 (All Others Skip to L24)

L21. Think about your child's last hospital stay, how many nights was it?

Enter Number: _____ (acceptable range is 0-50 nights)

If L19 ≥ 3 (All Others Skip to L24)

L22. Now the stay before that one – how many nights was it?

Enter Number: _____ (acceptable range is 0-50 nights)

If L19 ≥ 4 (All Others Skip to L24)

L23. Now the stay before that one – how many nights was it?

Enter Number: _____ (acceptable range is 0-50 nights)

L24. Think about all the doctor's offices and clinics (CHILD NAME) visited for health care in the last 6 months. In total, about how many visits has (he/she) made? (Your best estimate is fine.) Was it:

PROBE: Include all of your child's health care in your answer, not just care related to asthma.

- | | |
|-----------------|----------------------|
| 0 None | 2 4 to 6 |
| 1 1 to 3 visits | 3 More than 6 visits |

L25. During the last month, how many days did your child's health keep (him/her) out of school or day care all or most of the day?

Enter Days _____ (0-31)

PROGRAMMING NOTE: If child is under age 5 (item G in first module less than or equal to 4) **Skip to L27.**

L26. During the last month, how many days did your child's health keep (him/her) from taking part in after-school sports or physical education in school?

Enter Days _____ (0-31)

Language

L27. What language do you usually speak at home?

- 1 English → Skip to L29
- 2 Spanish
- 3 Other (Specify) _____

L28. In the last 6 months, how often did you have a problem communicating with your child's doctor or nurse because of language differences? Was it:

- | | |
|-------------|-----------|
| 1 Never | 3 Usually |
| 2 Sometimes | 4 Always |

Marital Status and Household Composition

L29. At this time, are you married or living with a partner?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

L30. What is your current living arrangement? Right now, are you living . . .

(CODE ALL THAT APPLY)

- 0 Alone
- 1 With your spouse or partner
- 2 With your children or others who are related to you,
- 3 With others who are not related to yo

Employment

L31. Right now, are you working for pay?

- | | |
|-------|--------------------|
| 1 Yes | 5 No → Skip to L33 |
|-------|--------------------|

L32. During the last month, about how many days of work did you miss because of (CHILD NAME)'s health?

Enter Days _____ (0-31)

Income

PROGRAMMING NOTE: Text of L33 should be conditional to coding of L29.

L33. Now I have a question about total income for you and your spouse or partner. Income can come from a number of sources: like salaries, wages, social security, welfare, dividends, interest, and any other income. Think about your and your spouse's or partner's total income 1999. Would it amount to \$30,000 or more?

- | | |
|---------------------|------|
| 1 Yes → Skip to L35 | 5 No |
|---------------------|------|

L34. Would it amount to \$15,000 or more?

- | | |
|---------------------|--------------------|
| 1 Yes → Skip to L36 | 5 No → Skip to L36 |
|---------------------|--------------------|

L35. Would it amount to \$50,000 or more?

- | | |
|-------|------|
| 1 Yes | 5 No |
|-------|------|

Home Ownership

L36. Do you own or rent your home?

INTERVIEWER: If R's parents or family own the home, code it as "own."

- 1 Own
- 2 Rent
- 3 Exchange work for rent or some other rent-free arrangement

STUDY ENROLLMENT AND FOLLOW-UP

We will send you a \$10 check for completing this interview. I want to be sure we have your correct address and phone number.

The address I have for you is:

Street: _____

City: _____ State: _____ Zip: _____

Is this correct? 1 No 5 Yes

What is your correct address? ENTER CORRECTIONS OR NEW ADDRESS

Street: _____ State: _____ Zip: _____

The phone number I have for you is: _____

Is this correct?

What is your correct phone number? _____

>panel<

We would like to interview you again by phone about 12 months from now in order to find out about changes in your child's health and to ask about the care he/she receives over the next 12 months.

Even if you agree to a follow-up interview now, you can change your mind when we call you next year.

Do we have your permission to call you back about 12 months from now?

- 1 Yes
- 5 No

In case we have trouble reaching you next year when we do our follow-up interview we'd like you to give us information we can use to locate you.

Do you expect to move any time between now and [MONTH 12 MONTHS FROM NOW]?

- 1 Yes
- 5 No

Do you know the address you will be moving to?

INTERVIEWER: ENTER AS MUCH INFORMATION AS R CAN GIVE YOU NOW.

We'd like to have the name of a friend or relative who always knows how to reach you. We would only contact this person if we are unable to reach you by mail or phone next year for the follow-up interview. Is there a friend or relative that you always keep in close contact with (other than your husband/wife)?

1 Yes

5 No

What is his or her name and address? _____

What is your relationship to [fill L5a@1]?

- 1 Friend
- 2 Daughter/Son
- 3 Sister/Brother
- 4 Grandchild
- 5 Other Relative
- 6 Other

We respect your decision. To help the researchers in this study, would you mind telling me the main reason you don't want to do the follow-up interview?

You may remember that the letter from [fill SITE CO-SIGNER] of [SITE] and Dr. Emmett Keeler of RAND said that we would like to combine your answers to the interview with a review of your child's health care records at [SITE]. Your child's health care records include his/her medical charts, and any information [SITE] may have about the cost of his/her care, pharmacy use, tests and procedures, as well as general administrative data.

I'm asking for your permission to have a member of our study team look at your child's health care records at [SITE] to collect information RAND researchers can use to get the full picture of his/her care for asthma. Your decision is voluntary and will not affect the care he/she gets from [SITE]. Do you give your OK for our study staff to look at your child's [SITE] health care records?

IF NEEDED: Any and all information that can be used to identify your child will be kept confidential. Your interview answers and his/her health care record data will be used only for the purposes of this study. RAND will not release your child's information to anyone without your prior consent, except as required by law.

IF NEEDED: RAND will give [SITE] name a report that combines your child's information with the information we get from other patients treated there. All information will be reported as group summaries and other group statistics. No individual patient information will be given to your doctors or anyone else at [SITE].

- 1 Yes, can look at health care record
- 2 No, refuses health care record
- 3 Undecided at this time

That's all of the questions I have for you today. You should receive your \$10 check in the next 4 weeks. We'll send you a letter to remind you about the follow-up interview. Thank you for your help.